

Posters

15. Nursing/Psychosocial issues

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329 Preparing parents for the transition from paediatric to adult cystic fibrosis (CF) care

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Objectives: Research suggests preparation for transition should be family orientated, to address concerns of both the patient and their parents. A survey of parents of adolescents with CF (aged 13–17) at a UK paediatric CF centre identified several concerns relating to the transition process and an interest in receiving more information about these areas. This project aimed to deliver and evaluate an information giving event for parents, about transitions in CF.

Methods: Parents/carers of 101 adolescents, aged 13–17 years, with CF were invited to an information evening about transitions – to both adult care, and adulthood with CF in general. The event was planned and delivered collaboratively by staff from the paediatric and adult CF teams. Content was based on concerns identified through a previously conducted survey. Information relating to the adult centre, including cross-infection policies and the local transition pathway was presented. The event incorporated testimonials from recently transferred families and tips for successful transfer, alongside stories from adults with CF to illustrate positive achievements and hope for the future.

Conclusion: 31 parents (of 20 adolescents) attended the event and 22 completed feedback forms. All parents felt it was useful to have attended. Positive feedback related to: patient stories, increased confidence regarding transition, positive views of the adult team, information from adult team psychologist and encouragement for the future. This pilot transition event was successful and well received. The event will be incorporated into the local transition pathway and will be repeated with some modifications based on this pilot.

331 Looking at young kids with cystic fibrosis as students

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Young people with CF because of their recurrent hospitalization, are faced sometimes with difficulties in continuing their school journey. However, at the Hospital of Santa Maria, there is a school where a team of three teachers work, who give daily educational support to young people or, if they are isolated/immobilized, this support is given on the wards or in the rooms. More than work on their school works, they have the opportunity to participate in some projects developed here. One of them is named TeleAula Project, which goal is to promote interaction of students to minimize their isolation by making video calls with a team that is prepared in advance.

The school emerged in 2003 through a protocol established and promoted by ANFQ (Cystic Fibrosis National Association) between various entities.

Young people with CF who have an individualized tracking is based on contacts with their schools of origin, which ensures their educational success, reassuring all actors.

In this presentation we will give special emphasis to the work done by these students during their hospitalizations.

330 The “Ready, Steady, Go” programme – Addressing the needs of those in transition

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“Ready, Steady, Go” is a generic programme, designed and implemented to address the challenges of transition. Medical, psychosocial and vocational needs of the individual are addressed by following a structured yet adaptable transition plan, supported by Young Persons Clinic Weeks. The document addresses issues common to all young people but allows the CF team to focus on the individual's specific strengths and needs. Introduction to the programme commences when the child is aged 11 years, coinciding with the natural development of moving to secondary school. A key principle throughout the process is empowering the young person to take control of their lives, equipping them with the necessary skills to function independently and confidently as an adult. The programme empowers the child to gradually take over aspects of their care whilst supporting parents as they handover responsibility to their child. All aspects of development are covered by the programme, ensuring that difficult topics are raised. Continuous use of the plan is enhanced by the attendance of an adult CF physician at two monthly adolescent CF clinics, establishing a therapeutic relationship with the child and family. Four times a year Children's Outpatients host Young Persons Clinic Weeks, where the environment and emphasis is on transition for the child, family and all staff. These clinics provide an age appropriate environment where the involvement of outside agencies can direct young people to appropriate resources. Collaboration of the plan and clinic weeks provides a tool for the CF Team and the patient to ensure a purposeful and planned transition to adult services.

332 Pulmonary status does not predict school attendance in children with CF

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Treatment in cystic fibrosis (CF) may entail hospital admissions which can be disruptive to schooling. Our centre facilitates continuing age appropriate provision of schooling facilities during hospitalisation. There is still a considerable variation in overall school attendance in our cohort of patients. We tried to explore whether this variation in school attendance was related to their Pulmonary status.

Objectives: To examine the correlation between Pulmonary status (FeV1 and number of inpatient hospital days) and school attendance in a single tertiary Cystic Fibrosis centre.

Methods: All school aged children with CF under the sole care of our CF centre, who had had an inpatient hospital stay in academic year September 2009–2010 were included. School attendance was ascertained from the Local education authority records. Medical records were examined to ascertain the best Fev1 and number of inpatient hospital days during the same academic year.

Results: 26 Patients with cystic fibrosis were admitted to our centre during September 2009–September 2010. Reliable data on school attendance was available for 12 patients. Average inpatient stay was 27 days/year. Average overall school attendance was 62% (Range 1.6–92.9%). There was no correlation between the FeV1 percentage and number of inpatient days and school attendance.

Conclusion: Pulmonary status (measured as FeV1 percentage and number of days of inpatient stay) does not predict the school attendance of children with CF in our experience. We postulate that other factors like educational status of the parents and families attitudes to illness and education may be responsible for this variation.